



The Staff Disability & Long Term Health Conditions Forum Presents

Spotlight #03: Working & Dealing With Severe Migraines

Producer / Host: Jesse James Kofi

Guest: Anonymous Female

DESCRIPTION

Today we are joined by a member of staff from Guys & St Thomas hospital trust who is dealing with having chronic and severe long term migraines

Our guest prefers to remain anonymous while they discuss how they cope with constant headaches and migraines as a long term health condition

We discuss the physical and mental effects this condition can cause as well as the challenges / outcomes this has presented in their current role

We lastly get specific with medicines involved to help control these conditions, new and promising prevention trials and even a charity that can help others in similar situations that may find such information helpful

Jesse: Friends and listeners, welcome to another episode of spotlight.

This podcast is brought to you in conjunction with the members of the staff disability and long term health conditions forum. We are so happy to have you listening, but more than that, I am so happy to be joined with, by another guest. Now this episode is going to be a little bit different, mainly because we have a guest here who prefers to stay anonymous. f

Now, this is something we've been talking about in the leadership team.

There's a lot of members of staff that work with the trust that have stories they want to share and experiences they want to share, but they don't feel comfortable disclosing who they are and what roles they are working and that is for various reasons that I really want to get into with our special guests.

So today's guest is anonymous, but they are someone that has been working with the trust for a number of years. Someone I consider a friend, someone I know and someone that has a story to tell, and I want to ask.... I want to have a dialogue with questions that I think is relevant, but first of all, welcome, and thank you for sharing your time with us to talk about a few things.

Guest: Hello. Thank you for having me

Jesse: It is our pleasure now, um, you have a long-term health condition, which is part of the focus of what I want to speak about and you've, allowed us to discuss that openly. And it's something that I have an experience with as well. So if you don't mind, would you mind telling us what your long-term health condition is and you know, your experiences?

Guest: Yeah. So, um, my long-term health condition is, um, basically I suffer with severe migraines. Um, they have been going on for the past, I'd say three years and yeah, they're, they can really affect my ability to work and just do normal day-to-day things. Um, like go to the shops, open the curtains, things like that.

Jesse: I know there might be a stigma with headaches being classed as a long-term health condition or disability, because I've suffered with them as well. And I've had brain surgery and as a result of that sometimes I'm prone to have migraines and headaches as well but if we look at the statistics and we look at the organizations, headaches or migraines can be a majorly rehabilitating condition that can have severe effects on your life and on your health and on your attitude and on your whole persona.

I mean, I, I could speak from that from personal experience, but I know again, knowing you. It's a bit more severe with you, but before we get more into that, would you mind just a little bit, I know you thought when it disclose too much about yourself, but what has been...

well, let me ask you this, you work with guys and St. Thomas trust, is that right?

Guest: Yeah, thats correct

Jesse: ...and you've been working with the trust for a number of years.

Guest: Yeah, I've been working with the trust for just over three years.

Jesse: Do you mind if I ask you if it's a more of a clinical role or more of an admin role.. or...

Guest: It's an admin role. So basically what I do is I'm a patient access coordinator. What that basically means is I do admin and book appointments.

Jesse: ...and how have you found it working for the trust so far - Guys and St. Thomas, how have you found it?

Guest: Um, I've found overall working for the trust has been good. I've had some challenges because of my health, but overall it's been good, especially coming from my previous line of work, when I compared it to, I'd say, it's overall been a good experience.

Jesse: So let's get back to the long-term health condition of having severe migraines. You said this developed.. would you say this developed all through your life or primarily now - because I think you've told me off mic in a previous conversation, that in your life, you have had it before, but at this time in your life, it's been a bit more pronounced - is that right?

Guest: Yeah. So, when I was younger, I had surgery quite close to the brain as well.

And from about the age of 4 to the age of 15, I suffered with quite severe headaches. Um, at the time the word migraine wasn't used, but I would say that they're on par with the headaches I'm getting now. After I was 15, they went away for a few years and then around the age of 23, they popped back up and they've been getting steadily worse since then.

Jesse: Just for those who don't understand, how it affects you, would you mind going into a bit of detail about how the migraines affects you physically?

Guest: More often than not. When I have a migraine episode, I get very severe light sensitivity. Um, I get sharp pulsating pains on the right side of my head. I have to remain in a dark quiet space if possible. I avoid going out. I can't do basic things like cook because heat seems to worsen the situation as well and it's just not a great time.

Jesse: and because of that, you just can't do your working role. You find that sometimes you just can't come to work.

Guest: Yeah. I've missed a lot of days of work, which obviously isn't ideal because of the trust sickness policy. Um, I physically can't look at any screens. I can't look at the computer. I can't look at my phone most of the times, I can't watch the TV. It's just literally, I need darkness and quiet until it passes.

Jesse: So it was really all consuming. You just can't do anything at all.

Guest: Yeah, it takes over the day and all you can focus on is the pain of that migraine until it goes away.

Jesse: ...and that must have a psychological effect as well. I'm assuming.

Guest: It does. I mean, it can make me feel bad about life. It can make me feel a bit stuck sometimes. And it's hard to see the light at the end of the tunnel sometimes because migraines is one of those things that there isn't really a cure for. There's only things that you can try and use to manage the pain, not necessarily, oh, take this for a few months and you'll be good to go.

Jesse: So what support or education have you found with dealing with the migraines, just because I know there's so much information out there, but since you've been on this journey, you've had so much time off work and you need support to help you, what elements have been there to help you in terms of information, support, guidance regarding the migraines.

Guest: Um, so I'm under the care of neurology. So they've been trying to help and advise.

Based on the amount of migraines I've been having, I recently, reached out to the migraine trust for some information, just basically for some advice regarding how it's affecting work. Um, just to go a little bit more into that, basically, because I've had so many days of work, it has triggered what they call a stage one proceeding, which is basically where they put you on a sickness plan.. and you're not meant to go over a certain amount of agreed days.

Obviously, because my situation has been getting worse. I've surpassed those days. So I wanted to reach out to the migraine trust to find out some advice on what my rights, are regarding having the condition I have being in the workplace and trying to keep a job.

Jesse: ...and what kind of advice did they give you? What kind of help did you get or advice?

Guest: So the advice I was basically given is... based on the amount of episodes I have a month, it could be considered a disability and therefore, if it is considered a disability, then it can not be counted towards my normal quota of sick days, because this is something that's completely out of my control. It's not a fluke, where for example, you might wake up one day with a stomach bug or a cold. It's not something like that. It's something where it is consistent and it is regular and there's not much I can do about preventing them at the moment. Um, but what they said is in order for it to be considered a disability, a clinician would need to write a letter.

Jesse: Right... and how...

Well, you're completely anonymous. I know that having people on to talk about these things, there's a lot of fear behind it.

If you feel comfortable, would you mind talking about how you felt your surrounding staff, your work mates have responded to, to this

Guest: Um, honestly, I, I feel like I work with quite a good team in general, and they've tried to be as understanding as possible, but at the same time, because they're managers, they have certain things and certain procedures and certain boxes they have to tick in a way.

So for example, they put me on the sickness proceedings and even though they say to me, if you're sick, you're sick. Don't worry about it. Don't come in because I'm on the sickness proceedings. It's always in the back of my mind - that I need to bear in mind how many days I've had off, which adds stress to the situation.

When you have a migraine, the last thing you need to be doing is worrying and stressing... and even though no one has come up to me and said, you have to come to work. It still does play on your mind because you know that they're not exactly happy with the amount of absences you've had, even though they try and be understanding.

Jesse: Um, so I, I know that from working with people in the past and jobs I've been food people have said they have had migraines and I think it's always been this common thing that people would always use "I've got a headache" or "I've got a migrate" to get out work or to get out of things... and because of that, there's the stigma that, you know, a migraine or headache is the easy get out of jail jail free card - You know, to not work.

So it's so hard to prove that it's chronic, especially with people that really suffer from it chronically and that's the big issue. I'm sure there's people that lie because people lie about everything. It's not just, um, headaches, any condition some people will lie to get out of work, but because it's so easy and it's not easy to determine a diagnosis and it's so difficult, I guess you guys are left in this gray area and that is what can make this so difficult.... am I right in saying that?

Guest: Yeah, I would definitely agree. I mean, migraines are up there with, the most common excuses for calling in sick and what I've personally found in my department is there are people there that say that they suffer migraines, but nobody seems to be on the same severity level as how I have them.

So definitely in the beginning, when I would say I have a migraine, I don't think they will fully, um, Grasping how bad they can be until one day I actually had a migraine episode start while I was at work... and my eyes were red, I was a bit disorientated.

They had to send me home and then I think that's when they really started to grasp that. Not all migraines are the same. Not everyone suffers in the same way.

Jesse: Yeah. It's uh, it's really tough. I have an interest in seeing what people go through, especially when we're about to have these interviews.

I try to educate myself by watching YouTube to watch materials. To listen to other experiences, and I saw that some people can have violent vomiting fits. Some people can fall unconscious. Some people can be hospitalized and I don't know.. because people use this so much as an excuse. It's like, do we have to wait to see that happen

Using you as an example, you are a very hard worker, I know you've got a good reputation for working. So when you say this is happening, you know, your colleagues have relied on you. You've won awards. You've done well in your role.

They believe you, just based on your character and on your work ethos. So it's much easier. But I guess my question to you is. From your perspective, what can be done to help?

I know just believing people would be nice, but looking around at all the things facilities which the trust has available, is there anything you could throw out there as feedback that can be, maybe, used to help them help you more?

Guest: Um, I think in general it would just help if people had more of an understanding of how severe migraine can actually be, um, more understanding on the fact that it's not just a headache. It affects multiple things at the same time and just a bit more patience with people that do so suffer with severe migraines.

..and one thing that would definitely help, which I don't think is going to have happen is dim-able lights in the office, but I think I'm asking a bit much.

Jesse: No, I like that. That's an actionable effect. Dimmable lights and the offices. A really good thing. Is there any tools you use in your day-to-day that you found helpful to help you have migraines apart from, you know, the basic over the counter medicines, which might not even work for you, but do you have any recommendations or anything that might help anybody else?

Guest: Um, so it's mainly for me, the things that help are mainly darkness and quiet. So if you can invest in a dimmable light bulb at home, if you don't already have one.

...and just make sure you have some windows in your house that's nice and quiet and dark if you do suffer from light sensitivity, um, making sure you're hydrated because dehydration definitely doesn't help with a migraine.

..and yeah, I think those are the main ones I would consider. Sometimes you just have to ride it out for me personally, a lot of the medication I've been prescribed hasn't worked. So it was just a case of. Take the medicines, see if it works and wait for it to pass.

Jesse: Let's talk about possible workplace adjustments.

Now I assume, and I might be wrong in assuming this but were you referred to occupational health at any time for this?

Guest: Yeah. I've been referred to occupational health. This will be the second time, because like I mentioned, things have gotten worse.

Jesse:and do they come over any suggestions as well on their end, occupational health

Guest: As of the last time I spoke to them, not really. They asked me to do a, um, desk risk assessment, which...

Jesse: what does that involve?

Guest: So it's basically just making sure that your computer screen is at the right height, your chairs at the right level there's space on your desk for you to have comfortable typing.

Jesse: Is that helpful at all?

Guest: It was not helpful. It's mainly more of an assessment of if your workstation is fit for purpose, more than anything else.

Jesse: Hmm.. I'm thinking of other things that might help, like, you know, giving you a chance like if you felt a migraine coming on that going into an empty office maybe, or going to a different floor somewhere more quieter.

Do you think they're possible reasonable adjustments they can make to people with migraines

Guest: Those are reasonable adjustments and, um, they did kind of suggest that, but because I work in such a big office, there's not many places that are quiet and for me, the major issue is the brightness, which you can't really escape unless you close your eyes.

Jesse: Okay, what about probably, maybe people listening, think this is the most obvious - what do you think about working from home as an alternative where you can control the environment, you can control the lights, control the noise, you've got the laptop. Do you think that could be an alternative long-term solution?

Guest: Yeah. I mean, that could definitely work. I mean, because of COVID, I've had to work from home some of the time during the week and that definitely helps because I can draw my curtains. I can make sure the lights are off and literally the only light I have in the room is the little bit of daylight coming through from the sides of the window and then obviously from the screen, which I can dim, so that definitely helps half of the time.

Jesse: Um, I really want more actionable things we can do, but I guess it all falls onto getting that diagnosis that severe migraine being an official disability or long-term health issue - basically, as you said before, your doctor or neurologist signing off on giving you that distinction that can be put through - that whole process, do you think it could be streamlined?

What can be done to improve that process? What do you feel needs to be. If anything could be done, I'm just throwing things out there....

Guest: That's a good question. When it comes to that whole process, I think it really comes down to who your clinician is..

Jesse: The neurologist, you really feel like it all comes down to the Neurologist / consultant that sees you.

Guest: Yeah. I mean, you have to speak up and ask these questions, but ultimately I feel like it comes down to the neurologist that sees you. Um, because honestly I've encountered

medical professionals that are very helpful and understanding, and I've encountered professionals that are not so understanding.

So it all depends on who you meet on the day in a way. Um, some people will be very understanding and give you what you need in order to make your work life a bit easier - other people are a bit more reluctant to go that extra mile, because it's not necessarily something that they have to do. Some people see it as an extra piece of paperwork to add to their admin that they don't really want to do.

Jesse: Yeah, so... i know you have a long list of medication that you have taken - just to further prove the point you've really been through it. Now, would you mind just going through some of the medication you've taken through the migraine saga to just illustrate your trials through these years, because I think its honestly interesting and again, this might help other people to know what's available to them as a possible treatment.

Guest: Yeah. So, um, where to begin...

So before I got my official diagnosis of migraines. It used to just be, Ibuprofen, Codine, Co-codamol things like that, which never worked.. and then when I got my official diagnosis, the first thing they put me on was Amitriptyline, which is commonly an antidepressant but can also work as a beta blocker for migraines.

Basically what a beta blocker does is it's meant to reduce the amount of migraine episodes that you get.

Jesse: don't beta blockers do something for the heart as well. I thought they were meant to control blood pressure as well.

Guest: So, um, in this case with the Amitriptyline it is mainly an antidepressant, so it doesn't really regulate blood pressure that much, as far as I'm aware, Um, but there's different types and I'll get onto the blood pressure ones next. So they basically gave me the Amitriptyline, which is an antidepressant, which as you can imagine, taking antidepressant anti-depression medication when you're not depressed, basically just turned me into a bit of a zombie, um, which was counterproductive because the whole reason I wanted to reduce my migraines was so I was fit for work and I wasn't fit for work on that medication.

I've also had Propranolol, which is a blood pressure medication, but again, they said that it is helpful in reducing the amount of migraines that you have that worked for me for about a month.. and then after that, it just stopped working, i don't know if my body got used to it, or if I had already exceeded the maximum dose but that did not work

The next one they tried me on after that was Candesartan, which again can be used to regulate blood pressure. That was the worst one possibly out of all three, because I actually felt like I was getting more frequent migraine episodes on that.

..and then of course you have medication from when you actually do end up having a migraine attack, so for pain management...

Jesse: So, everything you just mentioned was to deal with beforehand, but then during the episode you are meant to take something different as well

Guest: Yeah. So everything I mentioned before is something you have to take on a daily basis.

Jesse: How many pills for taking on a daily basis.

Guest: So you start off at a certain dose and you have to increase until you get to the maximum dose that they feel will be most effective for you.

You usually have to increase every two weeks. So for example, you might start off at 4mg. Then in two weeks time, they want you to go to 8mg, If it's still not working, you add another 4mg on top of that so you're at 16 and so on and so forth.

Jesse: So... at maximum, at the height of your you taking these pills, how much were you taking at one time?

Guest: So in terms of the number of pills, I would say I was taking six to eight pills a day, max, depending on what individual pill dosage was for the Propranolol, they wanted me to get to one 160mgk for the Candesartan they wanted me to get to 32mg, which I got to 24 and I gave up because I was seeing worse results than not taking it.

Jesse: All that medicine.. I mean, just taken that amount of pills. you told me a certain point, you were taking these, this number of pills and I just couldn't imagine that, that could be good for your liver, your kidneys, because all these medicines, I don't feel like medicine is a free magic pill.

A lot of these medicines have side effects and I didn't bring this up, but you're a woman, so you know, you have your cycles as well, which can be a contributing factor to your condition, am I wrong in saying that?

Guest: No, the closer you get to a period, the more prone to headaches you can become, um, depending on an individual basis, obviously when it comes to your monthly cycle, a period is all very individual. Some people go for a very rough time. Some people feel unpleasant for a few days, and then they're fine.

So all depends on how your body reacts to all of those hormonal changes anyway.

But going back to what you said about the medication, having an effect on the body. it's definitely a concern. In fact, the last medication I was on required blood tests on a regular basis to check renal function.

Jesse: Wow. That's a lot.

Guest: It is a lot, and that's not the only... that's only half of the migraine story.

There's the medication you have to take to actually manage the pain and the event that you do get a migraine episode.

Jesse: Should I even ask about that? I do want to keep it concise. I don't want, I don't really want to you know, make this into a long saga of like embellishment in your pain because that's, that's not the point.

I am just trying to illustrate the point that you're taking a lot of medicine and it's not working. Meanwhile, you're going to work. Meanwhile, you're looking for understanding, you know, you just want to do your job, right?

You just want to succeed and you want understanding, but you're dealing with physical, mental stress. Obviously these pills are costing you money as well. You're paying for these pills as well. So I was just, you know, layer upon layer upon layer.

And it's a lot and you, you know, you need more support, but there's a stigma of, you know, headaches been an excuse that everybody can use at any time, but your losing work you're in fear for your job, it really does sound like a lot.

You know, I've watched, you have the turmoil of this as well and you know, you're here during this, having this conversation with me anonymously because....

Let's talk about that. You don't want to come forward with your name and specific role about it, just because, and you know, to be honest, rightfully so...

There's something in the back of mind. That's saying, if colleagues know about this, they might hold it against me. I don't want to put words in your mouth without a lot to say about this. This that's a whole other subject when it comes to, you know, the perception of people disclosing your long-term health, condition or disability, or just feeling fearful of how it can affect you, but.....

How do you feel about that? Just coming forward to it and I respect your right and you wanting to just keep your personal details safe, but how do you feel about disclosing this?

Guest: I mean, part of the reason I want to remain anonymous is even though I do want to share my story, I don't want everyone to know my personal business in the sense that they can put a name to the voice. And I don't particularly want everyone I work with knowing everything I'm going through.

So it's an element of wanting to keep certain things private at the same time. I don't want a manager to be able to hear this and maybe take it the wrong way and then it starts affecting my job.

Jesse: No. Sorry, I didn't want to cut you, but, uh, I appreciate you for coming on and saying this. I really do. I don't take it lightly. And I've always said to everyone listening and everyone who is a perspective guest, you know, this isn't about putting people on the spot and exposing them. It's about raising awareness that I feel, you coming on and sharing your story is something someone else might relate to and might, you know, get courage to come forward and help you, help others and that's a great thing.

That's what we want to do we want to help. Of course we also want to create a safe space for people to talk and have these open conversations, whether they be a little bit negative and you get a little bit of pushback about things, but that's how we improve.

I really honestly think that's how we improve and I want to use this platform to do that. So I don't have a problem with anyone coming on anonymously talking about these things. I do understand that when you're anonymous, people can kind of abuse that and say things and make up things and just come and talk badly about an organization.

But at the same time, I still think there's a balance. Like you coming on here and saying your piece of saying your story and what you're going through. That's great. I honestly, I think it's courageous and it really is going to inspire people, but at the same time, we have to recognize that, you know, we can't all have it the way we want it.

If people need to come on anonymously to get things off their chest and say their story, it's honestly better than nothing. It really is. And we really, really, really, really appreciate that. And I guess this was kind of a test to see how it's received.

I really do. Thank you. And I do want to, I feel bad because I kind of twisted your arm into this a little bit in a kind of a jokey way, but you know that I would never just pressurize you to do this and I never want to pressure anyone to do this, but I just want you to remember, you, who I'm talking to you right now - what you're doing is helping so many people, honestly, and people listening right now. If you're silent and you feel that you want to be heard, but you don't want to do it, please come on.

Like our guest is doing right now. I won't disclose your identity. I will, you know, change your voice and whatnot, but I want to say this just to interject and slightly change the trajectory of the conversation

I was in, um, one of our meetings (SD & LTHC monthly meeting) and there was this bigger discussion about, you know - the fact that people feel that they will be, ostracized or looked down upon.

There was a lot of people when we had the meeting that was really hurt by the fact they couldn't be honest about their condition. They want to share their story, but at the same time, they felt that they might be put upon. And some of us felt really hurt by that, you know, cause organization, isn't just one person, its a whole group of people and we want to support. And the fact that people feel a certain way is, kinda.

It's just, it's disappointing. It really is disappointing, and maybe it's an organizational thing. Maybe it's something to do with us, I can't blame just the people that don't want to come on because I think people, you know, I'm sure that people out there might want to come on and tell stories where they disclose something to their manager and it was used against them.. even though they shouldn't have, because at the end of the day, we're all human and humans can be good. They can be bad and they can be biased and they can be helpful, but we've got to try to find a balance.

So we got to just try to correct the narrative and be careful. We want to walk that fine line of having data protection, respecting people's privacy, but at the same time, giving the people, the space to champion their stories and encourage others, which is something... it's a balance we're trying to find here with this podcast and with the trust in general. So yeah, I think that's kind of it. Um,

I don't want to speak for you. I just went on that little ramble there just because we are getting pushed back in certain ways. And a lot of people do want to tell this Louise anonymously, which are more than happy to do, but to be honest with you, I want to encourage both.

I want to encourage people to be their true selves, to say who they are, tell their story and not be afraid to do it or feel repercussions, but at the same time, if they don't do that completely understand, you want to let them tell their stories - the truth hurts sometimes but let us, let us just be real and tell these things and help us improve.

And I thank our guest for letting us do that with your story because I've had migraines that have kept me from working and then sometimes I have to leave work as well, but to your level, you know, it's something that needs to be respected and understood more and helped more. And some of the things you mentioned today, like the migraine trust and actually one thing you didn't mention, which is really cool is right now, there is a treatment that you are under, a new treatment that I wouldn't mind you talking about, which is very,

very, very new, which if you don't mind elaborating a bit on, there's been a little bit of a breakthrough with the migraine treatments.

Would you mind talking about that a bit?

Guest: Yeah. So there has been a breakthrough with the migraine treatments in the sense that they've come up with. Well, there's two drugs that are approved for the NHS to use at the moment, which have been designed specifically for migraines

All the medications I mentioned before were originally created for something else and then they realized that it does help migraines.

Whereas this has specifically been created from migraines. So basically what it does is it eliminates the need to take medication every single day. In theory, it's just a injection that you administer yourself once a month and it doesn't cure you of migraines, but it's meant to drastically reduce the amount that you have

Jesse: Do you remember the name of these?

Guest: So the one I'm taking is Emgality but I believe there's also one called Ajovy

Jesse: Yes, so I will put the links to this down in the description, you do have to be put forward to it by your neurologist right?

Guest: Yes, that's correct. my understanding is you have to have tried a certain amount of the normal tablets, the prescriptions, the preventatives

Jesse: The ones you mentioned before?

Guest: not necessarily, may not necessarily be the same ones based on your individual circumstance, but you have to have tried a certain amount of preventatives first and if they failed, then they will put you forward to the waiting list for one of these treatments to see if that works.

Jesse: Great resource, that's a great trial - it was approved right now for the both of those medicines you mentioned. But, um, I saw there was a YouTube video that was describing, it was a nurse, actually, someone who works in the NHS, they made a video talking about their experiences, with it as well, which I will link in the podcast subscription as well, which is really good.

There's also a YouTube channel called the headache channel, which is a great resource - it's an American channel, to be honest with you, but you know, America and UK have so much parallels in terms of the medicine. He spoke about Ajovy as well, a great resource, a channel that I forwarded to you as well, that you mentioned had some knowledgeable information as well, especially about taking medicine.

Um, so you self administer this medicine once a month. Is that right?

Guest: Yeah. So it's every four weeks to be accurate. Um, so basically when you go in to see your consultant or your nurse, they'll explain everything to you. They'll show you how it works. They'll show you how to administer it - and then what happens is when you're approaching your next dose, the medical courier will call you to arrange the delivery.

It gets delivered to your house, you put it in the fridge half an hour before you're going to administer it. You take it out of the fridge and it is a self-injected pen.

So it's quite easy to administer. They'll tell you the parts on your body that you can use it on. You just pick a site, sanitize it, which they also provide you with, inject yourself, make sure everything has gone in, and then they provide you have a sharps bin to dispose of the used, needles.

Jesse: Amazing, excellent. I saw this. it really does look great, you started this, so, you know, I'm really hoping that this works for you. You've only done it for a little while. I won't get into how long, but you find it for a little while so we're waiting to see, but the preliminary results and all the research behind it says more often than not percentage wise I think they said, um, well on the NHS website, did they say it was 40% effective or was that 80% I forgot the statistic there.

Guest: To be honest with you. I'm not too sure. I think I saw 40%, but that might have been for something else, so don't quote me on that

Jesse: yeah, this is fine. I'll link the studies in the podcast description, but it's really been a breakthrough, very positive feedback so far. So, yeah, anyone suffering from migraines might want to put this on their list, you know, something to be put forward for, but, um, I think we are going to stop here. It's been quite a meaty conversation.

I've learned a lot through your journey. I know you're still going through it, but we want to support you again. If anybody, has been through anything like this or got any more supportive information, any ways we can help. You know, please let us know a I'll put an email link down in the description, but I want to thank our anonymous guest for sharing this story phenomenal, thank you so much.

There's a lot of useful information there and we're going to wish you the best for the support of the trust and your colleagues and yeah. It's been really great so thank you.

Guest: Thank you for having me

Jesse: ...and listeners once again, thank you for the support, thank you for your interest, just like I said before, when I went on a little bit of a ramble, we really want to help anyone who wants to share their story.

We know that it feels like a barrier, sometimes, podcasting and speaking about these things live, but really, we're just trying to be as open and helpful as we possibly can be, so please come to the forums If you can.

Links will be in the description, we thank everyone for their time and yeah, we really do just want to help and we don't want to lose this opportunity.

We are funded by the trust to create these podcasts. We don't want to lose this platform, so please help me / us to do this more by coming on and sharing your story.

Thank you for listening.... and we'll see you on another recording.

Please find below links / resources mentioned during this conversation

The Headache YouTube Channel

https://www.youtube.com/channel/UCWtLYWoWW5Teahm0Cwu_VIQ

The Migraine Trust

<https://www.migrainetrust.org/>

AJOVY & EMGALITY DETAILED INFORMATION FOR PATIENTS

<https://www.nationalmigrainecentre.org.uk/migraine-and-headaches/migraine-and-headache-factsheets/cgrp-and-anti-cgrp-injections-for-the-prevention-of-migraine/>

Email address for the podcast enquires: j.kofi@nhs.net

To find out more information about the staff disability and long term health conditions forum please email: Disabilityforum@gstt.nhs.uk

Thank you for your continued support, please like and share our content with your communities and let us continue to promote, learn and uplift from each other!